TESTIMONY

OF

MR. KENNETH EDMONDS

MEMBER, NATIONAL BOARD OF TRUSTEES

CROHN'S AND COLITIS FOUNDATION OF AMERICA
386 PARK AVENUE, SOUTH
NEW YORK, NY 10016

PRESENTED TO THE

HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES

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SUMMARY OF FY07 RECOMMENDATIONS:

1) A 5% INCREASE FOR THE NATIONAL INSTITUTE OF DIABETES, AND DIGESTIVE AND KIDNEY DISEASES, AND THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES.

2) $700,000 FOR THE NATIONAL INFLAMMATORY BOWEL DISEASE EPIDEMIOLOGICAL PROGRAM AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION.

Chairman Regula, Congressman Jackson,

Good afternoon and thank you for the opportunity to testify today on behalf of the Crohn's and Colitis Foundation of America (CCFA).

My name is Kenneth Edmonds and I serve on the National Board of Trustees for the CCFA, the nation's oldest and largest voluntary organization dedicated to finding a cure for and to seeking to prevent Crohn's disease and ulcerative colitis.

Through research, education and support, CCFA is committed to improving the quality of life of children and adults affected by these diseases, collectively known as inflammatory bowel disease (IBD). I am one of them.

IBD is a chronic disorder that causes inflammation of the digestive tract. It affects approximately 1.4 million Americans, 30% of whom are diagnosed in their childhood. IBD can cause persistent diarrhea, severe abdominal pain, fever, and, at times, rectal bleeding. If complications develop, it also can lead to, among other conditions, anemia, liver disease and colorectal cancer.

Inflammatory bowel disease is often painful and debilitating. And, its impact is perhaps most devastating for children and adolescents, whose diagnoses often make them stand out at a time when they most want to fit in. Indeed, their disease can make them not only feel different, but look different as some adolescents with IBD may have delays in physical growth and puberty, causing them to appear younger and smaller than their peers. But, at any age, being diagnosed with IBD can bring change and challenge.

The news of my diagnosis came not in one, sudden rush, but rather in a long, gradual backslide -- and into a hospital bed. In retrospect, I exhibited typical signs of IBD as early as 1993 while a student in college. But, unfortunately, I responded to those signals like too many adolescents and young adults -- I overlooked them.

At the time, I experienced acute abdominal pain so sharp and sudden that I would double over. These cramps often came without warning, creating an intense urge to use the nearest bathroom. On these occasions and others, my stools had traces of blood.

But, because I was young and active, I didn't think that much about it. And, I certainly didn't talk about it, to anyone. I chalked these brief episodes up to my regimen, rather than my abdomen. I figured that I just needed to add more greens to my diet and add more hours to my sleep.

But, by 1996, after moving to Chicago, my symptoms had become too persistent, too serious and too severe to ignore. By the summer of that year, I had developed sores or ulcers on my tongue, making it difficult and painful to eat. I lost appetite and lost weight.

In addition to the persistent diarrhea and acute cramps, I also had developed a tear (a fissure) in the lining of my anus, which caused excruciating pain and bleeding during bowel movements. I also suffered from severe exhaustion.

As you can imagine, this was an agonizing predicament: I was losing weight, but could not eat. I was fatigued, but could not sleep. I had frequent, sudden bowel movements, but they caused sharp, piercing pain. Indeed, I had deteriorated dramatically; my condition relegating me to somewhere between bedridden and bathroom-bound.

A misdiagnosis, three, long, withering weeks, and a plane ride later, I found myself in the Washington Hospital Center under the care of my uncle, a gastroenterologist here in the District. After a series of tests, X-rays and examinations, I was diagnosed with Crohn's colitis and prescribed medications for my symptoms. Since my hospitalization ten years ago, I am pleased to report that the disease has been in remission and I have enjoyed relatively good health. I'm one of the lucky ones. For many, their lives continue to be interrupted, punctuated and hampered by painful flare-ups because they do not respond well to current treatments.

After all, Mr. Chairman, IBD is a life-long disease. While there are drug therapies to treat symptoms, there is no medical cure. And, its cause is unknown.

That's why CCFA's work and mission have been so critical and groundbreaking. By funding cutting-edge studies and financing promising research, the foundation has been involved in every discovery and advancement in the field of IBD.

RECOMMENDATIONS FOR FISCAL YEAR 2007

1) NATIONAL INSTITUES OF HEALTH

In fact, CCFA has developed incredibly successful research partnerships with the NIH, forging longstanding collaborations with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which sponsors the majority of IBD research, and the National Institute of Allergy and Infectious Diseases (NIAID). CCFA provides crucial “seed-funding” to researchers, helping investigators gather preliminary findings, which in turn enables them to pursue advanced IBD research projects through the NIH. This approach led to the identification of the first gene associated with Crohn's -- a landmark breakthrough in understanding this disease.

Mr. Chairman, CCFA's scientific leaders, with significant involvement from NIDDK, have developed an ambitious research agenda, titled "Challenges in Inflammatory Bowel Disease" that outlines and seeks to address the many opportunities that currently exist. Fortunately, the field of IBD is widely viewed within the scientific community as one of tremendous potential.

To help capitalize on these opportunities, CCFA recommends that the Subcommittee provide a 5% increase in funding for NIDDK and NIAID in FY07. Moreover, CCFA requests that the Subcommittee encourage these two institutes to expand their IBD research portfolios at a similar rate.

2) CENTERS FOR DISEASE CONTROL AND PREVENTION

IBD EPIDEMIOLOGY PROGRAM

Mr. Chairman, as I mentioned earlier, CCFA estimates that 1.4 million people in the United States suffer from IBD, but there could be many more. We do not have an exact number due to these diseases' complexity and the difficulty in identifying them. There could be many more with IBD who, like me, were misdiagnosed or, out of embarrassment, are suffering in silence.

We are extremely grateful for your leadership in providing funding over the past two years for an epidemiology program on IBD at the Centers for Disease Control and Prevention. This program is yielding valuable information about the prevalence of IBD in the U.S. and increasing our knowledge of the demographic characteristics of the IBD patient population. If we are able to generate an accurate analysis of the geographic makeup of the IBD patient population, it will provide us with invaluable clues about the potential causes of IBD.

Unfortunately Mr. Chairman, the President has eliminated funding for this important program in his FY07 budget for the CDC. CCFA encourages the Subcommittee to restore support for the IBD Epidemiology Program at last year's level of $700,000.

Once again Mr. Chairman, thank you for the opportunity to testify. I would be happy to answer any questions you may have.

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